DOCUMENT RESUME

ED 150 798 EC 103 913

AUTHOR Randolph, Linda
TITLE Diagnosis and Assessment of Handicapped Children in Head Start. Executive Summary Report.
INSTITUTION American Academy of Pediatrics, Evanston, Ill.; Westinghouse Population Center, Columbia, Md. Health Systems Div.
SPONS AGENCY Administration for Children, Youth, and Families (DHEW), Washington, D.C.
PUB DATE Oct 77
CONTRACT 100-75-0062; 105-76-1005
NOTE 21p.; Document may not reproduce well in hard copy due to the color of paper in the original

EDRS PRICE MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS *Clinical Diagnosis; Early Childhood Education; Exceptional Child Research; *Handicapped Children; *Identification; *Program Evaluation; *Student Evaluation
IDENTIFIERS *Project Head Start

ABSTRACT

Presented is an executive summary of the findings and recommendations from an information gathering effort on the screening, diagnosis, and assessment of handicapped children in Head Start programs. Information gathering activities were noted to focus on three major areas: identification and utilization of diagnostic resources, development of a team approach to the diagnostic evaluation of handicapped children, and parent involvement and participation with diagnostic resources and/or teachers. Among recommendations offered are that Head Start programs need to maximize the integration of the components of administration, education, health, parent involvement, and social services; and that training and technical assistance methodologies involving records and reports should first identify and deal with possible attitudinal barriers. A paper on diagnostic criteria for reporting handicapped children in Head Start is attached. (SBH)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED150798

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

DIAGNOSIS AND ASSESSMENT OF HANDICAPPED CHILDREN IN HEAD START

Executive Summary
October 1977

Office of Human Development Services
Administration for Children, Youth and Families
Department of Health, Education, and Welfare

As part of a reorganization of the Office of Human Development -- now Office of Human Development Services -- the name of the Office of Child Development was changed in July 1977 to the Administration for Children, Youth and Families. This change is reflected in this document on the cover only.

EC103913

THIS IS THE EXECUTIVE SUMMARY OF A REPORT
PREPARED FOR:

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of Human Development Services
Administration for Children, Youth and Families

Under Contract Nos. HEW-100-75-0062 and HEW-105-76-1005
Linda Randolph, M.D., M.P.H., Project Director

HEW-100-75-0062: AMERICAN ACADEMY OF PEDIATRICS, DEPARTMENT OF COMMUNITY SERVICES

RICHARD OLMSTED, M.D.
ACTING DIRECTOR
DEPARTMENT OF COMMUNITY SERVICES

ROBERT J. CLAYTON, M.D.
COORDINATOR-DIRECTOR
FOR THE HANDICAPPED

AUDRA PAMBRUN, R.N., DSc.
ADMINISTRATIVE DIRECTOR
HEAD START MEDICAL CONSULTATION SERVICE

LAURENE KEMP, M.A.T.
ADMINISTRATIVE ASSISTANT
FOR THE HANDICAPPED

HEW-105-76-1005: WESTINGHOUSE HEALTH SYSTEMS

E.C. CURTIS, M.D., M.P.H.
PROJECT DIRECTOR

ROBERT J. CLAYTON, M.D.
COORDINATOR,
HANDICAPPED PROGRAM

BURTON L. CORDRY
DEPUTY PROJECT ADMINISTRATOR

LINDA ROSEVEAR-GREENBERG
SPECIAL PROJECTS COORDINATOR

INTRODUCTION

Head Start has always had a national policy of open enrollment for all eligible children, including handicapped children. As noted in the Head Start Manual of 1967 "Head Start encourages the inclusion of mentally and physically handicapped children in an integrated setting with other Head Start children."

The legislative mandate passed in 1972 requiring Head Start programs to provide at least 10 percent of the national Head Start enrollment opportunities for handicapped children made Head Start programs begin an affirmative outreach and recruitment program to find handicapped children and enroll them in Head Start. The Headstart, Economic Opportunity, and Community Partnership Act of 1974 strengthened this approach by requiring that the 10 percent enrollment mandate be by State.

The intent of this mandate for Head Start programs is to (a) serve handicapped children in an integrated setting or mainstream environment with other children, (b) provide for the special needs of the handicapped child, (c) work closely with other agencies and organizations serving handicapped children in order to identify handicapped children and provide the full range of services necessary to meet the child's developmental needs.

The Headstart, Economic Opportunity, and Community Partnership Act of 1974 also requires the Secretary of HEW to report annually to the Congress on the status of handicapped children in Head Start including the numbers of handicapped children enrolled, the types of handicapping conditions and the kinds of services provided. The legislation defines handicapped children as those who are "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired or other health impaired children or children with specific learning disabilities who by reason thereof require special education and related services." Outside the scope of this definition are children with correctable conditions who do not need special services or who will not require altered or additional educational or support services.

In order to assist local Head Start programs with appropriate reporting of handicapped children, diagnostic criteria further clarifying the above listed definitions have been developed by the Office of Child Development in conjunction with numerous agencies and organizations such as the American Academy of Pediatrics, the American Psychological Association, the American Speech and Hearing Association, etc., who work with handicapped children.

Professionals working with Head Start programs to confirm that a child is handicapped are to use the legislated definitions and the diagnostic criteria to report a child as handicapped. This approach does not preclude the professional using diagnostic criteria or procedures that go beyond those stated herein for the purpose of developing an individual plan of services for the child. The Office of Child Development feels strongly that the determination that a child is handicapped is the responsibility of the professional diagnosticians, not local Head Start staff. This means that each Head Start program should maintain a diagnostic file about a handicapped child which includes (a) a functional assessment of the child indicating what the child can do and where his/her areas of need for special services are and (b) an individualized program plan based upon the child's functional assessment. Teachers' observations and measurements of a child's functioning become a part of this file as well as formal testing and diagnostic results. In addition, the Head Start program must develop a system to provide information to classify each child's handicap in relation to the categories spelled out in the legislation for the purpsoe of reporting to Congress. This system need not necessarily be "child specific."

The Diagnostic Process at the Local Level

There appears to be a trend that where adequate diagnostic resources increase in availability, more handicapped children are enrolled in Head Start programs. It is therefore necessary for local programs to identify this resource capability. This might be a diagnostic and evaluation center, a University Affiliated Facility or the Medicaid Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) which will pay for these services for Medicaid-eligible children or individual professional diagnosticians.

The assessment of a handicapped child frequently requires the participation of several disciplines. The professionals in medicine, psychology, special education, speech pathology, physical therapy, etc. may each spend time evaluating a child and must coordinate their activities with parent and teacher observations so that the total child is being considered. This diagnostic team approach provides the opportunity for not only the establishment of a diagnosis but also for development of recommendations for the provision of services. Some professional diagnostic resources already exist as teams with representation from the many disciplines. The Head Start program, however, must often take the responsibility for coordination of the professionals involved, and working with the parents to be able to continue this coordination effort after the child leaves Head Start.

Whenever parents, Head Start staff or other agencies and groups identify children as being handicapped, Head Start programs must ensure that the initial identification is confirmed by professionals trained in assessing handicapping conditions.

In addition, throughout the course of the handicapped child's enrollment in Head Start, his/her functioning must be observed on an ongoing basis and the assessment carried out on a planned, periodic basis that takes into account the dynamic process of growth and development. Careful procedures must be instituted for confidentiality of program records to insure that no individual child or family is mislabeled or stigmatized with reference to a handicapping condition. The principle to be followed is that the purpose of screening, diagnosis, and needs assessment for all children in Head Start is to ensure that program services are individualized to meet each child's needs.

The process of mislabeling a child is equivalent to misdiagnosis. This could lead to outcomes detrimental to the child. First and foremost, a diagnosis is related to provision of appropriate services. Thus a misdiagnosis (mislabel) will provide for inappropriate services. A child can be mislabeled by placing him/her in an incorrect diagnostic category because of (1) failure to recognize ethnic and cultural factors, or normal developmental stages or (2) through the utilization of inappropriate assessment techniques and procedures.

In 1975-76 the Office of Child Development undertook an information gathering effort in selected Head Start programs to look at the state-of-the-art of the diagnostic process at the local level. This was done through a contract with the American Academy of Pediatrics and in conjunction with other national professional organizations who work with handicapped children.

The effort looked at the relationship between diagnostic providers and Head Start programs in the areas of (a) identification and confirmation that a child is handicapped for reporting purposes, (b) development of recommendations for individualized program planning, (c) relationship of teachers and parents to the diagnostic process, (d) types of diagnostic provider arrangements -- i.e., team, solo, "roving" team, State or local facility, etc. This effort has resulted in an analysis of these and other variables with recommendations for policy and training and technical assistance activities in the area of diagnostic resource capability at the local level.

The following summary report represents the participation of Head Start staff members and a cadre of one hundred professional consultants in 14 disciplines who shared a common dedication to assist children with handicaps to realize their full potential.

DIAGNOSIS AND ASSESSMENT OF HANDICAPPED CHILDREN IN HEAD START

This document is an executive summary of the findings and recommendations from an information gathering effort on the screening, diagnosis, and assessment of handicapped children in the Head Start program. A field study and resultant draft reports were completed in the fall and winter of 1975 for the Office of Child Development (OCD) by the American Academy of Pediatrics. The incorporation of suggestions and recommendations from reviewers of the draft report was completed by Westinghouse Health Systems in the spring of 1976.

The Head Start program has been mandated by law to provide a comprehensive developmental program for preschool handicapped children. The legal mandate has further stipulated that the number of handicapped children should represent at least 10 percent of the total number of children served by the Head Start program in each State. Appropriate screening, diagnosis, and assessment is one of the areas of the Head Start program for handicapped children required by the Office of Child Development to meet its legal mandate.

The issue of diagnostic and assessment services at the local level has been raised in two reports and in Congressional committee hearings. The possibility of misdiagnosis and therefore provision of inappropriate services were two areas of concern raised in reports and hearings. The high percentage of children reported as speech impaired and health impaired was also identified as a potential problem area.

The Office of Child Development has relied on training and technical assistance to improve the delivery of various services to Head Start children. The purpose of this report was, therefore, to gather information to be used in planning those training and technical assistance activities to focus specifically on the diagnostic, and assessment services for handicapped children. The primary audience to whom the report is directed are training and technical assistance providers, policy planners, and program planners and providers of service at national, regional, State, and local levels.

The purpose of the field study and report was to identify and analyze indepth the barriers to effective diagnosis, and assessment of children with handicaps in order to improve future training and technical assistance planning and services. It was not to confirm or deny the previously cited concerns about service provision in a representative sample of Head Start programs. The programs participating in the information gathering effort were specifically selected because they had previously

reported incidences of handicapping conditions which seemed either significantly higher or lower than Head Start national norms as reported to the Congress. Although the sampling mechanism does not permit generalization of these findings and recommendations to other programs at this time, it was assumed that several of the problems identified could, to some degree, be characteristic of many Head Start programs. The applicability of these findings and recommendations for other Head Start programs will be done through regional training and technical assistance mechanisms.

The study began by reviewing and analyzing existing information, such as pertinent legislation, OCD regulations, policies and guidance materials, a National Survey questionnaire results and its Report, and a Government Accounting Office (GAO) Report. On the basis of the analysis, three major areas were identified for study in the information gathering effort:

I. IDENTIFICATION AND UTILIZATION OF DIAGNOSTIC RESOURCES

II. DEVELOPMENT OF A TEAM APPROACH TO THE DIAGNOSTIC EVALUATION OF HANDICAPPED CHILDREN

III. PARENT INVOLVEMENT AND PARTICIPATION WITH DIAGNOSTIC RESOURCES AND/OR TEACHERS

The report focuses, therefore, on these areas since they have presented implementation problems for OCD policies. Each area was looked at in terms of existing information and information generated by the site visits to a nonrandom sample of thirty-five programs. These information gathering activities resulted in three categories of recommendations:

A. Training and technical assistance to local programs.
B. Office of Child Development policy and practices.
C. Future research, development, and demonstration.

A case study methodology was utilized to gather new information. A questionnaire was developed and used to obtain information on 106 handicapped children in 35 Head Start programs throughout the country. Each case study involved interviews and completion of a questionnaire with Head Start administrative staff, diagnostic provider, family member(s), and Head Start teacher, all of whom were involved with the same handicapped child. The 100 interviewers were specially trained interdisciplinary consultants representing the fields of: Administration, Architecture, Education, Law, Nursing, Nutrition, Occupational Therapy, Pediatrics, Physical Therapy, Psychiatry, Psychology, Religion, Social Work and Speech and Hearing. The results and recommendations from the case studies were assembled into a draft report which was then sent for review and comment to members of an interdisciplinary advisory committee,

local participating programs, regional offices of the Office of Child Development, and national professional and parent organizations concerned with handicapped children. Comments from respondents were then incorporated into the final report.

I. IDENTIFICATION AND UTILIZATION OF DIAGNOSTIC RESOURCES

Most of the report's data concerns the area of resource identification and utilization. OCD policy and guidance directs Head Start programs to insure professional diagnoses by persons trained in assessing children with specific handicaps to confirm the initial identification of a handicapped child. Previous information had identified the professionals used for diagnosis as:

- private physicians, psychiatrists and other medical professionals — 55 percent
- other qualified professionals, including psychologists, speech pathologists, etc. — 27 percent
- Professional, qualified Head Start staff — 17 percent

The Head Start staff was not identified in terms of professional disciplines.

Results from the sampled programs showed that Head Start programs utilized two major groups of diagnosticians. About 25 percent of the children were reported as diagnosed by teams which means that more than one professional was involved in the diagnostic process. The majority of these professionals were employed by public or voluntary agencies and were located in urban areas. The second group, representing about 75 percent of the diagnosticians, were not members of a diagnostic team. They constituted most of the diagnosticians available in rural areas of which over 60 percent were private practitioners, predominantly physicians, psychologists and speech pathologists.

OCD policy and guidance suggest that the diagnostic providers could be best utilized in prescribed ways which include:

- Diagnostician uses the legislated definitions and the diagnostic criteria to report a child as handicapped.
- Diagnostician provides information in such a way that it can readily be reported in the annual survey.
- Diagnostician undertakes functional assessment of child.

- Diagnostician provides recommendations, based on the functional assessment, that allow parents, teachers, and others to best work with the child.

- Diagnostician guards against misdiagnosing a child (mislabeling) as handicapped by: (1) recognizing ethnic and cultural factors and normal developmental stages; and (2) utilizing appropriate assessment techniques and procedures.

In other words, diagnostic resources when effectively utilized should provide Head Start programs with:

1. A Categorical Diagnosis - a report assigning the child to one or more of the ten categories of handicapping conditions using the specific diagnostic criteria developed for this purpose in Head Start.

2. A Functional Assessment - a report describing an individual child's functioning and areas of need; e.g., what a child can do and areas to be improved.

3. Recommendations for Teachers and Parents - a report, whenever feasible, should contain recommendations for teachers and parents which would be appropriate to the child's developmental level and needs. Recommendations in this form are more readily utilized by Head Start programs in developing an individualized plan for the child.

These activities should reflect an awareness of cultural, ethnic, and developmental considerations and accordingly use appropriate instruments and assessment procedures.

Previously collected information indicated that a professional categorical diagnosis was documented in about 75 percent of the reviewed Head Start records. A professional functional diagnosis was found in only about 25 percent of the records. One concern raised from the record review was that the lack of documentation might represent misdiagnosis either as to the category or the degree of functional impairment. As a result, the individual child or family might be exposed to unjustified labeling or stigmatization.

The results from the sample studied showed a documentation level of about 75 percent for the categorical diagnosis and about 65 percent for the functional diagnosis. The lack of documentation for a categorical diagnosis did not necessarily represent a misdiagnosis, but rather indicated the absence of a written categorical diagnosis from the diagnostic provider. There were no instances found where the Head Start program considered a child handicapped and the diagnostic provider considered the child non-handicapped. The major reason for undocumented records was

the diagnostic provider's unawareness of Head Start's need for such information. Almost all of the diagnostic providers interviewed had never seen the legislated categories or diagnostic criteria. Once presented with the information, over 75 percent of them reported their willingness to use the desired reporting categories.

The nearly 25 percent who reported that they would not report in the legislated categories gave philosophical reasons for their refusals. Those who refused were mainly concerned with the categories of mental retardation, serious emotional disturbance, and the health or developmental impairment subgroup related to hyperactive children. The most frequent reason given was the conviction that most preschool children cannot with certainty -- and therefore should not -- be placed in one of the three categories. Most who shared these feelings also cited the considerable professional and lay literature which discussed the dangers of labeling, and their concerns about the possibility of malpractice suits.

Diagnostician concern about mental retardation, serious emotional disturbance and health or developmental impairment also contributed to the high incidence of speech impairment reported by some programs. Many mentally retarded and emotionally disturbed preschool children have concomitant communication problems. Some diagnostic providers and Head Start staff reported a tendency to assign a child to the least potentially stigmatizing category for reporting purposes.

The lack of documentation of functional diagnoses seemed mainly attributable to the diagnostic provider's lack of awareness or understanding of the need to report in functional terms rather than to misdiagnosis. Many diagnostic providers expressed their willingness to provide this type of diagnosis in the future. Other providers, particularly physicians in private practice, did not see functional diagnoses as within their professional responsibility or interest. Some expressed the belief that Head Start staff were in a better position to provide functional diagnoses. A similar point of view was also expressed by diagnostic providers in providing specific recommendations for the individualized care of the child on a day-to-day basis by the teacher and/or parent. A lack of agreement and standardization on the content of individualized plans was noted. Over 40 percent of the teachers had no written individualized plans. As a result no documentation of the use of diagnostic recommendations was available.

An attempt was made to address the problem of mislabeling by asking diagnostic providers what special considerations, techniques, and/or testing they used if a child was from a minority group. About 60 percent of the children in the sample, it was found, had been diagnosed from tests with standardized norms. There were no examples of tests designed specifically for a particular minority group, although some of the tests were administered in the child's native language. A number of speech

and language diagnosticians reported that they had to evaluate test results in the light of their knowledge of local dialect patterns found in economically disadvantaged populations. A consensus among consultants and reviewers was that additional information was needed in this area.

Highlights of the recommendations derived from the collected information are:

A. DIAGNOSTICIAN - HEAD START COMMUNICATION

Primary emphasis should be placed on raising the level of awareness and communication between diagnostic providers and Head Start programs:

1. Head Start programs need to be made aware of the necessity of their obtaining written documentation for both categorical and functional diagnoses.

2. At the beginning of the program year, Head Start programs should make their needs known to diagnostic providers. This is best accomplished by individual or group face-to-face meetings. The agenda for the meeting should include, but not be limited to:

   a. Presentation and discussion of Diagnostic Criteria for Reporting Handicapped Children in Head Start.

   b. Reporting procedures, including use of simplified reporting forms.

   c. Procedures for safeguarding against labeling and stigmatization, minority group testing, and preparation of individualized plans.

3. Head Start programs need to be aware of which services diagnostic providers will provide. It must be recognized that many diagnostic providers are not trained to provide all three: a categorical diagnosis, a functional diagnosis and recommendations for teachers and parents.

4. Head Start programs should have a provider service profile for each diagnostician. An adaptation of the questionnaire used in the information gathering effort could be used to obtain this information which would allow programs to identify service gaps. In many cases Head Start professional staff could fill these gaps after receiving minimum training and technical assistance.

B. THE ISSUE OF POTENTIAL LABELING AND STIGMATIZATION

Two approaches are recommended for addressing the problem of potential labeling and stigmatization:

1. Develop a dual record system. The categorical diagnosis would remain at a central location and the functional diagnosis would be entered in the child's record at the Head Start center.

2. Begin a training and technical assistance program to destigmatize the categories of emotional disturbance and mental retardation. This could best be accomplished as part of a continuing community education program in conjunction with national parent organizations or other groups.

C. MINORITY TESTING

Head Start's concern with the testing of minority group children is shared by the Office of Education. The latter's new legal mandate is to assure "tests and evaluation materials are not racially or culturally discriminatory" (PL94-142). It is recommended that the Office of Child Development and the Office of Education jointly explore this area of mutual concern at both the federal and local levels.

D. INDIVIDUALIZED PLANS

Office of Child Development guidance in the development of individualized plans is needed before diagnostic providers can be used most effectively in assisting Head Start staff to develop plans. It is difficult for diagnostic resources to provide information in a format which assist plan development without criteria, definitions, or guidelines of an acceptable plan.

II. DEVELOPMENT OF A TEAM APPROACH TO THE DIAGNOSTIC EVALUATION OF HANDICAPPED CHILDREN

The second area in which information was gathered was on the implementation status of OCD policy and guidance encouraging the use of multidisciplinary diagnostic teams. There is currently no OCD definition of a multidisciplinary diagnostic team. For this project's purposes a definition was developed which defined "multidisciplinary" as consisting of three or more professionals of different disciplines or specialties. Although the ideal would be that teachers and parents also be members of the team, this report looked at the professional diagnosticians represented on the team, with and without teacher and parent participation.

No data was available on the use of teams by Head Start programs. In the sample studied, one-third of the children had been diagnosed by multidisciplinary teams, one-sixth of which were composed entirely of medical specialists. Only one team would diagnose all ten categories of handicapping conditions. All Head Start programs in the sample utilize multiple diagnostic providers including teams and individuals.

One trend noted was for Head Start programs to form or use existing teams consisting of Head Start program component directors. These teams were involved mainly with intake, translating professional reports, and developing individualized plans. There was no Head Start team that considered itself to have a diagnostic function. Another trend found was the utilization of either a Head Start staff person as a member of a community diagnostic team for a specific child or of a professional to join the Head Start staff team around a specific child. Forty percent of the individual practitioners reported that they had been involved in similar types of ad hoc teams in their community in the past.

Three types of teams were defined by the study findings:

1. Internal Teams - teams consisting of members of Head Start staffs from three or more components with parents and teachers represented.
2. External Teams - teams consisting of three or more non-Head Start Staff from:

   a. different professional disciplines (interdisciplinary)

   b. different specialists within a professional discipline (intradisciplinary)

3. Combined Teams - teams consisting of an internal team member as a consultant member to an external team or vice versa.

Highlights of the recommendations derived from the collected information in this area are:

A. DEVELOPMENT OF INTERNAL TEAM CAPABILITY

Primary emphasis should be placed on "mainstreaming" the handicapped program into the responsibilities of all Head Start components, with the development of an interdisciplinary team capability within Head Start programs which would supplement existing community resources for diagnosis and ongoing assessment.

1. Head Start programs need to maximize the integration of the components of administration, education, health, parent involvement, and social services.

2. The handicapped program needs to be included as part of the overall effort for component integration with the formation of an internal team of component directors.

3. One of the functions of the internal team would be an ongoing assessment and review of each handicapped child which would provide ongoing diagnostic information.

B. DETERMINATION OF EXTERNAL TEAM CAPABILITY

Community resources such as diagnostic and evaluation clinics, University Affiliated Facilities, etc. often have existing teams of professionals which Head Start programs can utilize for diagnosis and assessment of handicapped children. Head Start personnel need to determine to what extent such a resource can provide the (1) categorical diagnosis for reporting, (2) functional assessment, (3) individualized program plan.

C. DEVELOPMENT OF A COMBINED TEAM CAPABILITY

The staff interchange between Head Start programs and outside diagnostic providers to form combined teams appears to be the best way to assure that all three parts of diagnosis and assessment are provided. Head Start programs need assistance in integrating their staff and consultants from other teams and vice versa.

III. PARENT INVOLVEMENT AND PARTICIPATION WITH DIAGNOSTIC RESOURCES

The third area in which information was gathered was on the status of implementation of OCD policies and guidance requiring parent involvement. Policies and guidance are not restricted to the parents of handicapped children, but are applicable to all parents.

Existing information from the*Third Annual Report indicated that services had been provided to about one-third of the parents of handicapped children in Head Start. The information was not in a form to permit determination of the level of parent participation or the extent of their involvement in screening, diagnostic or assessment services.

*The Fourth Annual Report December 1976 states that approximately the same proportion of parents received services.

Information was gathered on parent participation by developing a six-step model of the diagnostic process. Direct parent involvement at each step, as well as secondary involvement through teacher participation, was ascertained. The information was obtained from diagnostic providers, parents and teachers, and their responses were compared for extent of agreement. The findings showed a clustering of parental involvement into three groups -- high, intermediate and low levels of participation -- based upon the active role taken in each step.

High level participation accounted for about one-third of the sampled parents. The majority of the parents had a low level of involvement, and it was the consensus of the diagnostic providers that a large number of the families could not meaningfully participate in the diagnostic and assessment process. The families were felt to require a great deal of preparation and motivational stimulation which the diagnostic provider had neither the time, staff, nor funding to provide.

Less than one-sixth of the teachers reported active involvement in the diagnostic process. As a consequence, teachers did not feel they had sufficient information or skills for a secondary involvement in assisting parent participation in the diagnostic and assessment process. A majority of parents perceived the Head Start teacher as having a role in interpreting diagnostic and assessment findings and having complete responsibility for their child's program.

Highlights of recommendations derived from the collected information in this area are:

A. PARENT PARTICIPATION

Primary emphasis should be placed on the recognition that Head Start parents are at various levels in their abilities and willingness to actively participate in the planning and care of their children.

1. Head Start programs need to have alternative parent involvement programs related to parental ability and willingness to participate.

2. Those parents of handicapped children who demonstrate ability and initiative for active participation should receive training and technical assistance for meaningful participation with both internal and external teams.

3. Following training, technical assistance, and practicum experience, the parents who are able and interested in parent participation should be utilized in assisting other parents to take part in the program.

B. TEACHER PARTICIPATION

Teacher participation in external teams does not appear to be a meaningful strategy for most programs. A more realistic approach would be to involve teachers as members of internal teams whose function is to consider the program of each handicapped child. The individualized plan with parent participation should be the focus around which diagnostic and assessment information is utilized and integrated.

Information was also collected on the priorities of diagnostic providers, teachers, and parents for future training and technical assistance to provide direction for implementing the recommendations in the three major areas. The major findings were:

1. The most frequent recommendation of all groups was that no additional training and technical assistance was needed in the areas of screening, diagnosis, and assessment. One reason given to explain this was satisfaction with current services. Another was their feeling that the area was of low priority, considering the limited time available for participation in training and/or technical assistance activities. Many of those who gave this reason felt they had greater needs in other areas.

2. Technical assistance related to the management of specific children was expressed by a majority as being preferred to group training activities. These latter training activities were described as usually being too broad and too general to be able to be translated into a concrete plan for a particular child.

3. Training or technical assistance in administrative areas, such as records or reports, was often perceived as a necessary evil -- unrelated to helping the child. Required information was most often viewed as a distracting and time consuming endeavor which was collected for someone else's use. Many expressed the feeling that this attitude was widely shared and was, therefore, a significant barrier to any training and technical assistance activities involving records or reports.

Highlights of the recommendations derived from the collected information are:

A. NEED PRIORITIES

Recognition needs to be given by training and technical assistance planners and providers that their need priorities

may not be shared by the recipients of such activities. The effectiveness of training and technical assistance activities can be increased by allowing recipients to participate in self assessments of their own needs. An instrument such as the Self Assessment/Validation Instrument (SAVI)* with items in the area of screening, diagnosis, and assessment would be helpful in meeting this need.

B. TRAINING AND TECHNICAL ASSISTANCE METHODOLOGIES

Training and technical assistance methodologies involving records and reports should:

1. First identify and deal with probable attitudinal barriers.

2. Use a case study approach or Head Start staff, who have successfully used records or reports, to illustrate how records and reports are relevant to individual children, families or programs.

*The Self Assessment/Validation Instrument (SAVI) is a management tool designed to help grantees evaluate how well they are providing the program services (or meeting the Head Start Program Performance Standards).

ATTACHMENT

DIAGNOSTIC CRITERIA FOR REPORTING HANDICAPPED CHILDREN IN HEAD START

All children reported in the following categories* must have been diagnosed by the appropriate professionals who work with children with these conditions and have certification and/or licensure to make these diagnoses.

Blindness

A child shall be reported as blind when any one of the following exist: (a) child is sightless or who has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning; (b) a determination of legal blindness in the State or residence has been made; (c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

Visual Impairment (Handicap)

A child shall be reported as visually impaired if central acuity, with corrective lenses, does not exceed 20/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle of no greater than 140 degrees or who suffers any other loss of visual function that will restrict learning processes, e.g., faulty muscular action. *Not to be included in this category are persons whose vision with eyeglasses is normal or nearly so.*

Deafness

A child shall be reported as deaf when any one of the following exist: (a) his/her hearing is extremely defective so as to be essentially non-

*Multiple handicaps: Children will be reported as having multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions are present.

functional for the ordinary purposes of life; (b) hearing loss is greater than 92 decibels (ANSI 1969) in the better ear; (c) legal determination of deafness in the State of residence.

Hearing Impairment (Handicap)

A child shall be reported as hearing impaired when any one of the following exist: (a) the child has slightly to severely defective hearing as determined by his/her ability to use residual hearing in daily life, sometimes with the use of a hearing aid; (b) hearing loss from 26-92 decibels (ANSI 1969) in the better ear.

Physical Handicap (Orthopedic Handicap)

A child shall be reported as crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include for example spina bifida, loss of or deformed limbs, burns which cause contractures, cerebral palsy.

Speech Impairment (Communication Disorder)

A child shall be reported as speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement; and speech and language disorders accompanying conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapped conditions, and other sensory and health impairments. *This category excludes conditions of a transitional nature consequent to the early developmental process of the child.*

Health Impairment

A child shall be reported as health impaired who has an illness of a chronic nature or with prolonged convalescence including, but not limited to, epilepsy, hemophilia, severe asthma, severe cardiac conditions, severe anemia or malnutrition, diabetes, or neurological disorders.

Mental Retardation

A child shall be reported as mentally retarded who, during the early developmental period, exhibits significant sub-average intellectual functioning accompanied by impairment in adaptive behavior. *In any*

determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (i.e. finding of a low I.Q. is never by itself sufficient to make the diagnosis of mental retardation).

Serious Emotional Disturbance

A child shall be reported as seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This category would include but not be limited to the following conditions: dangerously aggressive towards others, self-destructive, severely withdrawn and noncommunicative, hyperactive to the extent that it affects adaptive behavior, severely anxious, depressed or phobic, psychotic or autistic.

Specific Learning Disabilities

A child shall be reported as learning disabled who has a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. *For preschool children, precursor functions to understanding and using language spoken or written, and computational or reasoning abilities are included.* Such a category does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental disadvantage. (Professionals considered qualified to make this diagnosis are physicians and psychologists with evidence of special training in the diagnosis of learning disabilities and at least Master's degree level special educators with evidence of special training in the diagnosis of learning disabilities.)